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ABSTRACT

The document offers proceedings of a four session workshop titled "Community Programs for the Handicapped," a program to enable participants to inventory and explore community alternatives to the institutionalization of handicapped individuals. Session 1 addresses the concept of normalization and the availability and utilization of community programs for the handicapped. Session 2 looks at provision of programs for the handicapped within the public schools and through a community agency (specifically the Easter Seal Society for Crippled Children and Adults). Problem areas interfering with the concept of normalization are outlined. A third session offers guidelines for securing and improving community programs for the handicapped. The final session discusses the three major principles of normalization: integration, self determination, and normal risk. Appended are a list of participants, a paper on techniques of informal advocacy, a list of legal references, and sample forms. (SW)

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Community Programs for the Handicapped

Proceedings of a Workshop

June 17-19, 1982

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Preface

The workshop "Community Programs for the Handicapped" was designed to enable the participants to inventory and explore community alternatives to the institutionalization of handicapped individuals. Emphasis was placed on the concept of normalization and its application to various community settings. Participants critiqued the concept of normalization and its implementation in selected programs serving handicapped persons.

Workshop Schedule

Thursday, June 17, 1982, 1:00-5:00 p.m.

Registration
An orientation to the concept of normalization
The availability and utilization of community programs for the handicapped

Friday, June 18, 1982, 9:00-4:30 p.m.

Providing community programs for the handicapped
Securing and improving community programs for the handicapped

Saturday, June 19, 1982, 9:00-11:30 a.m.

A critique of the concept of normalization
Summary and conclusions
Adjournment

Workshop Objectives

To enable the participant to identify resources within their community which have been developed to provide alternatives to the institutionalization of handicapped individuals.

To enable the participant to prepare a critique of the concept of normalization as developed by Wolf Wolfensberger.

To enable the participant to assess the implementation of the concept of normalization in selected agencies/programs within their community.

To enable the participant to identify relevant procedures for implementing the concept of normalization in the organizations to which they belong.

Session One

An Orientation to the Concept of Normalization

Richard K. Myers

Normalization is a term frequently used and abused. The term often is used as a synonym for mainstreaming in the public schools and deinstitutionalization in the community. It has been used to justify both the denial of needed specialized services to and the need for specialized programs and/or services for handicapped individuals. The very simplicity of the term probably promotes confusion and permits misinterpretation.

Normalization is a concept that originated in the Scandanavian countries but has been refined and extended in the United States. It originally was used to describe an outcome to be achieved by the mentally retarded (Bank-Mikkelsen) or a process to be used in the treatment of the mentally retarded (Nirje). The concept was expanded by Wolf Wolfensberger to include both a process and an outcome to be used with all handicapped individuals.[1]

In order to understand and critique the concept of normalization and its applicability to and implementation in community programs for the handicapped, the essential elements of the concept must be identified.

Definition. The definition of normalization has evolved over the years as the concept has been refined. The present definition proposed by Wolfensberger states that normalization is the

> "..utilization of means which are as culturally normative as possible, in order to establish, enable, or support behaviors, appearances and interpretations which are as culturally normative as possible."[2]

Normalization does not mean to make "normal". The concept implies that if we want to help handicapped individuals look and behave as normally as possible, we must treat them as normally as possible.

Deviance Theory. The concept of normalization is based upon the notion of deviancy. Individuals are viewed as deviant when they meet three criteria: (1) they differ significantly from others, (2) this difference is in some characteristic which is viewed as relatively important, and (3) the difference is negatively valued. No clear criteria exists to define deviancy. Deviancy is in the "eyes of the beholder" and is culturally bound, i.e. individuals are labeled as deviant when they are perceived to be deviant. A historical review of the treatment of handicapped individuals would produce a chronology of different treatment approaches used with various handicapped groups related to the perceptions of deviancy held by the populance of the period toward various handicapping conditions. However, the devaluing of handicapped individuals is a common recurring theme.

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[1] Wolfensberger, W. The principle of normalization in human services. Toronto: National Institute on Mental Retardation, 1972.

[2] Wolfensberger, W. The definition of normalization. In R. J. Flynn and K.E. Nitsch (Eds.), Normalization, social integration, and community services. Baltimore: University Park Press, 1980, p. 80.

Deviancy Imagery. An important aspect of normalization is the avoidance of the imagery of deviancy. The use of methods, procedures, personnel, etc. with handicapped individuals which are viewed as odd, different, etc. may transfer to the handicapped individual and reinforce the perception of deviancy. Consequently, a full implementation of the concept requires the use of methods, procedures, staff, facilities, etc. which are perceived as being as "normal" as possible. For example, the use of elderly individuals as Foster Grandparents to young mentally retarded children may reinforce the deviancy imagery of both groups since both groups presently are viewed as deviant and devalued.

Valued Imagery. By connecting people, places, activities, etc. that are valued with handicapped individuals who are devalued may bestow or transfer some of the value to the handicapped person by association. For example, placing a group home in a desired residential neighborhood may encourage or increase the acceptance of the residents of the home.

Conservation Corallary. The fewer the ways a person is perceived to be different from others, the less deviant they will be considered and the less they will be devalued. Avoiding a "retarded look" via appropriate dress, grooming, behavior, etc., should reduce the degree of deviancy and increase the acceptability of the person involved. Recent proposals to employ surgery to improve the physical appearance of infants with Downs Syndrome by the elimination of traditional physical stigmata is an example of one approach to normalization.

Process vs. Outcome. Some people view any process as acceptable and appropriate as long as the desired results are obtained, e.g. the use of physical restraints to control self multilation. Others view the outcome as dependent upon the process employed and would restrict the process to one that is viewed as within a normal repetoire of treatment, e.g. the use of behavior modification and/or medication to reduce self multilation.

Ideological origin. Normalization is not research or experientially based. There is only a limited empirical foundation for the concept. As an ideology, it is a way of looking at things, a way of behaving toward others, a system of values. Normalization needs largely to be accepted on faith in much the same manner in which one accepts and practices political and sociological ideologies.

Normative behavior. A distinction must be made between what most people view (accept/value) as normal behavior and how statistically most people actually behave. Normalization does not require that the handicapped person achieve behaviors and appearances which are statistically normal but that their behaviors and appearances are within culturally acceptable and valued limits. In other words, a young handicapped person does not need to be taught how to become drunk or engage in premarital sex to achieve normalization. None or limited drinking and sexual abstinence are culturally acceptable and should not interfere with the goals of normalization.

Integration. A basic element of normalization is the integration of handicapped individuals into our society. Nirje[1] identified six (6) categories of integration:

1. Physical integration. Handicapped persons should have access to the same physical environment as nonhandicapped individuals.

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[1] *Nirje, B. The normalization principal. In R.J. Flynn and K.E. Nitsch (Eds.), Normalization, social integration, and community services. Baltimore: University Park Press, 1980.*

2. Functional integration. Handicapped persons not only should have access to the normal physical environment, but also be able to function within that physical environment.
3. Social integration. Handicapped persons should be able to interact with others and receive normal regard and respect.
4. Personal integration. Handicapped persons should be able to develop meaningful personal relationships with others.
5. Societal integration. Handicapped individuals should be able to function as a citizen and have the right to self-determination.
6. Organizational integration. Handicapped persons should be able to use generic community programs and services to meet the majority of their needs.

Stepwise incremented normalization. Normalization is not an all or nothing proposition. It is a goal to be achieved and, as with most goals, it consists of numerous enabling or subordinate goals. The level of achievement of normalization will vary for each person but can be achieved to some extent by all handicapped persons. For example, a severely mentally retarded child may not be able to learn to become fully self sufficient in grooming but may be able to learn several basic grooming skills such as brushing teeth.

(Re)valuation. The returning of value to a devalued person. (Re)valuation is a concept very close to normalization and may be thought of as a synonym for normalization.

Staff modeling. Modeling is related to valued and deviancy imagery. Individuals who work with the handicapped must recognize that they serve as models for their clients and may either encourage or discourage normalization by the behaviors and attitudes they express. In addition, the imagery they create among the nonhandicapped as a result of their behaviors probably will be bestowed (transmitted) to the handicapped individuals with whom they work. For example, a staff member who openly demonstrates an alternate life style may not only encourage their handicapped clients to mimic the life style but also encourage nonhandicapped persons who view the life style negatively to transfer this attitude to the handicapped clients with whom the person works.

PASS. The Program Analysis of Services System[1] is an evaluation instrument which has been developed to assess agencies and programs to determine the extent to which they are implementing normalization. To the best of our knowledge, PASS is a unique assessment instrument in that it is designed to evaluate the implementation of an ideology. An inspection of PASS will provide the reviewer with a comprehensive overview of the concept of normalization.

The Availability and Utilization of Community Programs for the Handicapped

Panel of Consumers
(D. Ross, M. Swayne, W. Vanderzwaag)

D. Ross indicated that her handicapped child, M, will be 16 years old soon. Her pregnancy was normal without complications, however, the infants' birth was assisted by instruments which probably resulted in brain damage. The child was 18 months old before a diagnosis was made. M is multihandicapped

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[1] Wolfensberger, W. & Glenn, L. Program analysis of service systems: A method for the quantitative evaluation of human service systems. (2nd ed., 2 vols.) Toronto: National Institute on Mental Retardation, 1975.

(cerebral palsy, mental retardation, and seizure disorder). The child does not walk (creeps), has very limited speech (gestures), and is not toilet trained (habit trained). When M was first born, there were few programs available for children like him in the community. The parents were on their own and had to develop their own programs. As a result of the lack of programs and services, Mrs. Ross has become an advocate and is actively involved in several advocacy agencies. She believes parents are the best advocates for their child and other handicapped individuals. Different problems develop and need to be resolved as the child becomes older. She feels fortunate that the timing has been right, up to this point, in that programs have been developed in the community as M has reached a point where a particular program is needed. However, she expressed concern about the future and hopes community programs will be developed for low functioning retarded adults. She doesn't want M to be institutionalized. She feels strongly that M has been an asset to the family and that the family is more understanding and compassionate of others as a result.

Mrs. Ross identified a number of problems which are of concern to her including:

- the need for day programming for low functioning retarded adults, including sheltered workshop and CLA services.
- the possible reduction in funding for special education programs and services.
- the need for transportation services for handicapped individuals and their families living in rural areas.

W. Vanderzwaag described S as a young child who has been diagnosed as autistic. S is nonverbal but is beginning to sign. There were no problems with pregnancy and initial development was normal until S was about two years old. Obtaining appropriate community programs has been a problem. Presently S attends a private Christian school because of the lack of appropriate public school programs for autistic children within their intermediate unit. Mr. Vanderzwaag believes that many autistic children are "buried" in special classes for mentally retarded children. Specific problems to the family which have been created by having an autistic child include:

- the child cannot keep up with the "flow" of the family.
- social activities need to be rearranged.
- the child needs to be "occupied" at all times to prevent withdrawal.
- much of the family's resources must be diverted to the child.
- social rejection.

Due to the constant need to deal with S and work with the child, it is easy to become "tired" of the child. However, the presence of S has forced the parents to become advocates both for their own child and other emotionally disturbed children. Mr. Vanderzwaag indicated that the family presently has two foster children who are either emotionally disturbed or socially maladjusted. The father identified a number of problems which are of concern to him:

- the funding of programs and services. Who is to pay for what is a major unresolved problem.
- the need for respite care, especially the availability of baby-sitter services.
- the need for information. Parents need to be taught how to handle their autistic children, especially when the family is in public.
- the need for support. Parents need continuing support.

M. Swayne described J as a preschool child with a moderate to severe sensori-neural bilateral hearing loss. J's loss was first discovered at age three months. Mrs. Swayne was expecting a problem because hearing losses are common on the paternal side of the family and typically follow an illness. Mrs. Swayne reported that initially she was told that J would "grow out of" the problem. When J was about two years old, personnel from the intermediate unit in which the family lives contacted the parents and offered to provide preschool services for the child. Audiological assessment and enrollment in a preschool program for hearing impaired children were provided. J wears a hearing aid and has made substantial progress. J will attend a kindergarten class for hearing impaired pupils in 1982-83 provided by the IU in an adjoining school district. A problem that still needs to be resolved is transportation since the family has only one car and the school district limits transportation to kindergarten to one way. The parents are in the process of resolving this transportation problem through the Due Process Procedures (PL 94-142). Mrs. Swayne reports that the family generally is satisfied with the progress J has made and the supportive services that have been available in the community.

A number of recurring problems were reported by the parents relative to having a handicapped child and securing appropriate and needed community services. The major problems included:

- Transportation. The lack of public transportation and/or the clustering of programs and services in urban areas creates major problems for the families of handicapped persons. While parents are willing to transport their children to needed services, the costs and time involved can become a real burden and influence attitudes toward the child.
- Information. The lack of information about needed and available programs and services creates a problem for families. If the family does not know a service exists or how to obtain access to a program, it cannot be used and may as well not exist.
- Financial. Limited family resources is a major problem for many families. Specialized services are costly and may drain resources from other family needs. The lack of or limited insurance coverage remains a problem for many families. Middle class families face a real dilemma since they frequently are not eligible for free services due to their resources yet lack the resources to pay for the services. Restrictions to family mobility may result since availability of needed insurance coverage may dictate employment.
- Recreation. Limited and/or inappropriate recreational facilities, especially in nonurban areas, may create real problems for families with handicapped children. Appropriate recreational facilities provide opportunities for family activities and may be useful in the development of skills in the handicapped child. In addition, appropriate recreational facilities provide opportunities for promoting social development and, in some instances, needed parent relief.
- Housing. The lack of community residential facilities for young handicapped children, low functioning retarded adults, and non-retarded handicapped individuals of all ages is a major problem in most communities. Appropriate residential facilities greatly reduce the need for and likelihood of using institutional placement for handicapped individuals.

- *Attitudes. The lack of acceptance of handicapped individuals by the community and the lack of needed community programs and services are directly related to the negative attitudes toward the handicapped person held by many people in the community.*
- *Labels. The use of labels with specific eligibility criteria frequently becomes a barrier to the receipt of needed community programs and services. Since funding usually is tied to labels and/or categories, handicapped individuals who do not meet specific eligibility criteria often are denied services due to restrictions imposed by the funding source. One example of this restriction is the CLA program which is not available to mentally alert handicapped individuals.*
- *Geratrics. A unique and growing problem is related to the increasing number of elderly handicapped individuals. The limited community programs and services for the population will need to be resolved if the elderly handicapped are to remain in the community.*

Session Two

Providing Community Programs for the Handicapped

Panel of Providers
(J. Asa and D. Musko)

Public Schools

Miss Jessie Asa, Director of Special Education, Butler Area Schools outlined the educational services provided by the Butler Area Schools for handicapped pupils. The Butler Area Schools is the largest school district in the three-county Midwestern Intermediate Unit. The District encompasses an area of 150 square miles and has a school population of approximately 10,000 which presently is declining. Approximately 10-11% of the student population (1100) are exceptional and were enrolled in special education programs during the 1981-82 school year. The District provides the following special classes: S/PMR (2), TMR (3), EMR (7), PH (2), LD (7), and SED (3). The District also provides School Psychological Services, Speech Therapy, and a Gifted Learners program. Midwestern Intermediate Unit supplies services for hearing and visually impaired pupils. A pre-school program for Hearing Impaired children also is provided by the IU. A few children receive their education in approved private schools (Western Pennsylvania School for the Blind and Western Pennsylvania School for the Deaf).

The goals of the special education program are the same as for any school, to provide a basic education program for all handicapped children and to take them as far as they can go in order to help them reach their full potential. The nature of the educational program provided is determined by the individual child and their unique needs. Services are available to handicapped pupils from 5 to 21 years of age. Miss Asa suggested that the incidence of handicapped children may be higher in the Butler Area Schools than some other school districts due to the clustering of families with handicapped children in the area as a result of the availability of community resources and transportation.

Miss Asa identified a number of problems which interfere with the maximum development of handicapped individuals. The major problems she identified included:

- *Funding cuts. The anticipated reduction in funds for special education may result in the curtailment of programs and services. She expressed the belief that preschool programs for handicapped individuals are likely to be hurt the most by funding cuts since they are not mandated by the School Code of the Commonwealth. Based upon her experiences, preschool programs are very important for the following reasons:*
  - *assist parents resolve emotional conflicts*
  - *provide parents with relief from 24-hour care*
  - *permit parents to focus on needs of their other children*
  - *help parents become involved with their child and learn parenting skills*
  - *help the child become independent*
  - *provide an opportunity to shape behavior and eliminate negative behaviors*
  - *promote language stimulation,*

- *Mental health needs. Some handicapped pupils need counseling services in order to achieve their potential. Presently the community mental health clinic is not funded to provide the type of supportive mental health services needed by many adolescent handicapped individuals. The schools need support from and interaction with appropriate community agencies to provide the needed services. The problem appears to increase as the handicapped child becomes older and approaches the end of the school years.*
- *Transportation. Handicapped children who live out of town frequently cannot take advantage of programs and services provided by the school which are not offered during the school day. Services and programs which occur after school hours or during the summer months usually are voluntary and do not include transportation. Consequently, handicapped children and their families who reside in outlying areas frequently are unable to utilize all available programs and services.*
- *Health needs. The specialized health services needed by many handicapped children are not available in the community. Consequently, many families need to take their children to Pittsburgh for services or do without. The time and costs involved are prohibitive for many families.*
- *Coordination of services. Although many programs for handicapped children exist in the school and community, obtaining those needed by a specific child requires considerable coordination effort and cooperation. The Butler School District and PARC Productions (sheltered workshop) have developed a successful collaborative program. Mentally retarded pupils who are about to leave school are transported to PARC Productions where they are provided with a prevocational experience. This program is coordinated by the work study counselor employed by the District. On the other hand, while the Butler County Vocational Technical School accepts some mildly handicapped secondary pupils for training, it does not now accept pupils who are moderately or severely handicapped. An attempt is being made at the present time to develop a collaborative program for these pupils with the Clarence Brown Special School, which is operated by Midwestern Intermediate Unit.*

Community Agency

Mr. Daniel Musko, Executive Director, Easter Seal Society for Crippled Children and Adults of Butler County described the programs and services provided by his community agency. The Easter Seal Society is the largest and oldest non-profit community agency that provides direct care services to handicapped individuals. The Agency originally was designed for crippled children, then extended services to adults, and now provides services to handicapped individuals from infancy to old age with seven major departments, which provide 25 services, operate three clinics, and employ a staff of 23 persons. The current budget is approximately $300,000 which is obtained largely from community support (e.g. United Way, clubs, organizations, etc.)

direct mail solicitation (Easter Seals), and contracted services (e.g. Department of Health, Butler County MH/MR, Butler County Memorial Hospital, etc.). While clients pay fees on a sliding scale, all clients pay something. It has been the experience of the agency that charging a fee, even though it may be only a token, results in greater progress and more personal involvement and responsible behavior from clients (e.g. keeping appointments) occurs then when services are completely free.

The primary purpose of the Agency is to provide habilitative and rehabilitative services to individuals who possess communication disorders, orthopedic disabilities, neurological or neuromuscular disorders, mental retardation, and other handicapping conditions which require one or more of the services provided. The three major roles of the Agency are education, advocacy, and direct care. The specific services provided by the Agency include:

- Speech and language screening.
- Speech and language evaluation.
- Speech and language therapy.
- Hearing screening (includes typanotomy).
- Preschool program for multihandicapped children.
- Language development preschool program.
- Transitional carry over (part-time preschool class for children on waiting list for language development class).
- Social services (includes case work services).
- Physical therapy.
- Equipment loan (free service but requires physicians' prescription).
- Public awareness/advocacy program.
- Information, referral, and follow-up services.
- Medical, clinic/brace assessment (orthopedic clinics).
- Third party programs (provision of contracted services to other agencies).
- Summer camping (one of five Pennsylvania Easter Seal Camps).
- Family Institute (conducted at one of the Easter Seal Camps).
- Adult day care program (low functioning mentally retarded adults).
- Deaf and hearing impaired services (includes interpreter services, social activities, and TTY Communication Center).
- Sign language classes.

Mr. Musko indicated that the Agency only recently began to provide services to individuals who are deaf. He views the deaf population as unique among the handicapped due to their isolation from the hearing world which frequently results in personal and social problems that need to be resolved. The services developed by his agency are intended to provide the support and resources needed by the deaf population.

Mr. Musko identified a number of problems related to the development of programs for handicapped individuals including:

- Transportation. The lack of public transportation and/or funds to provide transportation is a major obstacle for many handicapped individuals and/or their families.
- Information. Not knowing what services are available in the community or how to obtain the services are major problems for many handicapped individuals and/or their families. Some individuals lack the ability and/or resources needed to seek out the services they need.

- *Public Attitudes. Although some progress has been made in educating and developing more positive attitudes toward the handicapped among the public, many individuals continue to hold negative and/or inappropriate attitudes which interfere with the development of needed community programs and the achievement of habilitative and rehabilitative goals.*
- *Financial. Insufficient present funding and the likelihood of decreasing funds in the future have and will increasing impact negatively on many community agencies which serve the handicapped and their families.*
- *Housing. Additional residential facilities are needed in the community. The need is especially critical for individuals with severe emotional disorders.*
- *Recreation. Limited recreational programs in the community which are appropriate for and accessible to handicapped persons interfere with the social development of many handicapped persons.*
- *Elderly handicapped. Programs and services for the elderly handicapped person are generally lacking or insufficient for the community. Since this population is increasing, the gap between need and availability of programs and services is likely to increase.*
- *FLK. Mr. Musko believes that the "FLK" (funny looking kid) is a major problem for providers. The FLK is the child who has not as yet been diagnosed but appears to be in need of services. Since funding is frequently tied to labels and diagnostic categories or children with specific characteristics, the FLK presents agencies with a major dilemma.*

The concensus of opinion of the participants was that Butler County appears to have good programs and extensive services for handicapped individuals and their families. Public schools with administrators who are strong advocates for exceptional children will tend to provide comprehensive services of good quality. Private agencies with strong leadership will be able to secure the resources needed to provide programs and services to complement those provided by public agencies. The coordination and collaboration among agencies representing the public and private sectors should permit the community to provide a continuation of services of good quality to the handicapped person throughout their life span.

Summary

The participants identified a number of problem areas which appear to interfere with the implementation of the concept of normalization in the community.

Health. The lack of comprehensive medical services of good quality is a problem in many communities. Specific problems noted include:

- *lack of dental care especially for severely and multiply handicapped individuals,*
- *lack of health insurance - especially for multihandicapped - available coverage often incomplete and restrictive,*
- *lack of family physicians - especially for handicapped who return to the community from institution,*
- *lack of sensitivity to the needs and potential of handicapped individuals by many members of the health professions,*

Family. The presence of a handicapped individual in the family may create many problems for the family. Some of the problems noted include:

- *The lack of transportation. The need to provide transportation for the handicapped person not only involves considerable costs but also considerable time and effort and may result in resentment and/or limited utilization of available community resources.*
- *The costs involved. The handicapped person may require an inordinate proportion of the resources of the family.*
- *Family pressure. The presence of a handicapped person may put tremendous pressure on the marital relationship and create strain among siblings. Criticism from other family members, neighbors, etc. relative to treatment, child rearing practices, etc. may exerbate the problems.*

Educational. Handicapped individuals are increasing served by the public schools as a result of PL 94-142. However, specific problems noted included:

- *Funding. Program/service shrinkage is likely to occur as funds become tight.*
- *Nonmandated programs. Preschool programs are likely to diminish as a result of funding cuts and the lack of legislative and/or judicial mandates for preschool programs in Pennsylvania.*
- *Mainstreaming. Handicapped children are likely to be mainstreamed inappropriately in order to reduce the need for special education services with justification based upon normalization.*

Employment. Problems noted in the employment area include:

- *Programs. The number of existing prevocational programs are limited and need to be increased. Vocational technical schools need to develop training programs for moderately and severely handicapped. The handicapped need to be trained in areas that will increase their employability.*
- *Workshops. The limited number of workshops, eligibility criteria, and philosophy are problems that need to be resolved.*
- *Seniority. The "last hired, first fired" phenomenon is a major concern at this time due to the faltering economy.*

Citizenship. Several problems were identified which are related to citizenship. Specific problems include:

- *Voting. The lack of instruction in voting procedures, registration, and information relative to political issues have resulted in the failure of many handicapped individuals to participate in the political process.*

Recreation. A number of problems were identified which can be classified as recreational. These problems include:

- *Accessibility. While some improvements have been made, not all recreational facilities are accessible to handicapped individuals.*
- *Attitude. Negative and/or paternalistic attitudes frequently discourage handicapped individuals from participating in recreational activities which may be available within the community.*
- *Skills. The failure to encourage the development and to teach the needed skills, prevent many handicapped individuals from participating in recreational activities which are within their ability to perform.*

Spiritual. While considerable progress has been made in meeting the spiritual needs of handicapped persons, problems continue to exist including:

- *Accessibility. Many religious facilities remain inaccessible to handicapped individuals.*

Session Three

Securing and Improving Community Programs for the Handicapped

Panel of Advocates
(G. Grabe, P. Rosenbauer, and G. Russell)

Charles Grabe, Co-Executive Director, Mental Health Association of Butler County, briefly outlined the history of the MHA beginning with its origin in Butler County in 1952. Between 1952 and 1971 the association was operated by volunteers and a part time staff. In 1971 the first full time executive director was employed. The MHA was a prime mover behind the establishment of the Butler Mental Health Guidance Clinic in 1959. This clinic evolved into the present Irene Stacy Mental Health Center which provides comprehensive mental health services to all age groups. The MHA also was instrumental in the establishment of Transitional Living, Inc. which is a halfway house for individuals who have experienced mental health problems. Mr. Grabe indicated that the MHA presently has four major functions:

1. *Innovator of services-to establish and demonstrate the feasibility of services needed but not presently available within the community.*
2. *Public education - to inform the community about mental health issues through various media including speakers, pamphlets, etc.*
3. *Advocacy and social action - to utilize a variety of advocacy and social action techniques when needed in support of individuals and groups within the community.*
4. *Coordinate volunteers - to recruit and utilize volunteers in a variety of situations and activities related to the mental health needs of the community.*

Mr. Grabe expressed the opinion that the stigma associated with mental illness is the major barrier to obtaining the services needed. Many of the functions of the MHA are aimed at reducing and eliminating this stigma, i.e. public education, advocacy, etc.

Mr. Grabe defined advocacy as speaking for someone and an advocate as an individual who pleads the case of another. To be an effective advocate requires the advocate to use many different techniques dependent upon the issue and situation . The role of advocate may be assumed by anyone including those who are paid professional advocates and those who are merely interested persons. At one time or another most people can benefit from the services of an advocate. The advocate provides several important functions including:

1. *Assist the person define the problem so that it can be clearly stated to the provider.*
2. *Assist the person organize evidence to support their need for services to the provider.*
3. *Assist the person to enter the provider system, to be able plead their case via all appropriate channels and to appeal all subsequent decisions which do not resolve the problem.*

Mr. Grabe offered guidelines he believes should be considered by individuals interested in serving as an advocate for a handicapped person. His suggested guidelines include:

1. Be informed about the problem. Have all the facts and records.
2. Know the rules of the game. What are the relevant regulations, laws, policies, etc.
3. Focus on the client and their problem.
4. Help the client to help themself.
5. Plan your strategy and be prepared to adjust it.
6. Use the resources in your community.
7. Be creative.
8. Make your anger work for you.
9. Don't accept any excuses.
10. Follow up.

Mr. Grabe reviewed a handout "the techniques of informal advocacy", which was distributed to members of the MHA Board of Directors (See Appendix). He also suggested that individuals should read S. L. Stebel's book the shoeleather treatment[1], which is an account of the treatment of Bill Thomas while a patient at Fairview State Hospital for the Criminally Insane which is located in Pennsylvania.

Gail Russell, Executive Director, Association for Children With Learning Disabilities, Butler County Chapter, briefly described her agency. The ACLD has five primary goals:

1. To encourage, develop and establish educational and recreational programs for LD children.
2. To provide an opportunity for early intervention and identification of LD.
3. To assist families of LD children with numerous psychological, social and family problems resulting therefrom.
4. To provide an informal source of information for teachers and other associated professionals working with LD children.
5. To increase public understanding and awareness of the nature of LD.

The ACLD basically is a parent support group which also attempts to involve parents in working with their own and other children. Mrs. Russell believes the parent is the best and most effective advocate for their child, but the parent needs support in order to be effective. She described a parent support group project conducted by ACLD in Butler County during 1981-82 funded by the Developmental Disabilities Advocacy Network (DDAN). This project was designed to establish parent support groups in each of the seven school districts in the county.

Mrs. Russell identified two types of advocacy needed at the local level (1) class advocacy - representing the general needs of a specific group and (2) individual advocacy - representing the specific needs of an individual. It is essential that an advocate be informed in order to be effective. Among

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[1]Stebel, S. L. The shoeleather treatment. Los Angeles: J. P. Tarcher, Inc., 1980.

the things the advocate needs to know are:

1. *The law and where to find it.*
2. *How the law is enforced.*
3. *How to use the legal process.*
4. *The community and its structure.*
5. *The resources available within the community.*

Mrs. Russell believes that a good advocate "helps the child to help themselves", and facilitates the process by which one helps themselves or aids others to help themselves. The techniques employed vary somewhat depending upon the type of advocacy involved.

Class advocacy. Class advocacy often involves promoting community awareness. It is essential that the advocate knows what they are talking about. The advocate needs to know their subject, know what needs exist, know what solutions are possible, etc. The person needs to learn to use the media effectively and know how the political system in the community works. It is important to join appropriate community groups and keep others aware of the changing needs of the handicapped.

Individual advocacy. Individual advocacy often involves reconciling differences between providers and the individual's needs. It is essential that the advocate obtains all needed information and gets the facts straight. The advocate needs to establish an objective for their advocacy efforts. Specific suggestions offered include:

1. *Contact individual as close to the problem as possible. If unsuccessful at this first level, then progress to the next level.*
2. *Initially be as pleasant and tactful as possible.*
3. *Use anger effectively. Be firm, do not lose control, focus on the issue and do not get personal, i.e., do not "really" get angry.*
4. *Avoid playing attorney.*

Mrs. Russell stressed the importance of being a friend to the handicapped person.

The advocate can do a number of things to secure and improve community resources for the developmentally disabled, including:

1. *Speaking positively toward the issue.*
2. *Facilitating change to improve the quality of life.*
3. *Preventing injustice based upon prejudice.*
4. *Arguing in support of a cause.*
5. *Interceding on behalf of someone else.*

Mrs. Russell also shared a number of "helpful hints" she has found helpful in working as an advocate. These hints include:

1. *Maintain good records.*
2. *Make sure you understand the issue.*
3. *Don't go in with a hidden agenda.*
4. *Go in with a positive attitude.*
5. *Know what you want and politely and firmly go after it.*
6. *Let the parent do his own talking. You should reinforce their remarks.*

7. Serve as a negotiator, if possible.
8. Have a copy of the appropriate regulations, if any, with you and refer to them when necessary.
9. Use available resources.
10. Don't tie up large amounts of time. Allocate so much time to the meeting and stay on task.
11. Don't argue.
12. Know your options.
13. Be positive - offer constructive criticism.
14. Thank people for being helpful.
15. Be prepared - do your homework prior to the meeting.

Mrs. Russell shared several resources she developed with the participants. These resources included legal references, a list of advocates in Butler County and an Initial Case Intake Form used by ACLD (See Appendix). She also reported that the ACLD presently is undergoing a major reorganization due to severe funding cuts. A new agency will emberge from this process which will be different from the one she described.

Phillip Rosenbauer, Executive Director, Association for Retarded Citizens, Butler County, briefly described his organization. The major goal of the ARC is to promote the general welfare of mentally retarded persons. Presently, the ARC provides four major programs:

1. Community Living Arrangements - 14 CLA's serving 65 clients.
2. Park Productions - sheltered workshop serving 135 clients.
3. Growth and Development Center - pre-school program serving 12-15 children.
4. The Association - advocacy and public relations.

Mr. Rosenbauer described advocacy and public relations as similar, hence, there is no attempt at the local level to separate the two. Both functions are major functions of the ARC in Butler County as well as of the state and national ARC organizations. The State and National ARC organization provide support to the local chapter.

Mr. Rosenbauer identified two types of advocacy at the local level:

1. Class Advocacy - advocacy on behalf of the general needs of mentally retarded persons.
2. Individual Advocacy - advocacy on behalf of an individual mentally retarded person.

Two of the major functions of the ARC are to secure community services for mentally retarded persons and to improve those community services presently available to the mentally retarded. In securing community services, no attempt is made to separate advocacy from public relations. The ARC attempts to (1) make the community aware of the needs of mentally retarded individuals and (2) reconcile differences between these needs and available services. Improving community services is fostered by (1) encouraging ARC volunteers to serve on community committees and boards, (2) visiting and becoming familiar with existing programs, and (3) informing the community of the changing needs of handicapped persons.

Mr. Rosenbauer identified a number of techniques he has used which he believes are needed in order to be an effective advocate:

Group advocacy. The following suggestions were offered as helpful when dealing with group advocacy issues:

1. Know your subject and what needs exist.
2. Know the social services delivery system and the people who work within the system.
3. Employ local media.
4. Know the political system and how it works.
5. Always approach the issue in a positive manner.

Individual advocacy. The following suggestions were offered as helpful when working with individual advocacy issues:

1. Gather all the relevant information.
2. Establish clear objectives.
3. Don't get angry or lose control.
4. Be tactful and pleasant.
5. Contact people closest to the problem first.
6. Avoid playing attorney.
7. Use professional resources.

The panelist and workshop participants identified a number of gaps in the services provided by the community which should be of concern to advocates and advocacy organizations. The major gaps identified include:

1. Lack of information. The community remains unaware, misinformed or indifferent relative to the needs of the handicapped portion of the population. This lack of information frequently results in the failure of the community to provide and/or support needed services or, if provided and/or supported, to insist that the services are of the quality and quantity required.
2. Legislative inflexibility and ambiquity. Individual handicapped persons frequently are denied an existing community service due to their failure to meet the specific eligibility requirements or criteria established for receipt of the service. Intended services occasionally are not provided because no clear assignment of responsibility exists.
3. Inbalance of services. Services are not uniformally available to all segments of the population of handicapped persons. Availability of services frequently are restricted to those persons who have a specific label, are within a specified age range, reside in a specified geographical area and/or have access to public transportation, fall within a predetermined income level, etc.
4. Funding of services. The question of who is to pay for a needed service and/or the high costs associated with many services needed by handicapped persons interefere with the provision of comprehensive community services to handicapped persons. Inflation and recession compound this problem and may result not only in the failure to provide needed services but also the curtailment of existing services.
5. Utilization of services. Even where services are available, some handicapped individuals do not avail themselves of the services provided by the community. This problem was best expressed by Mr. Rosenbauer who commented "people with the greatest need are the most less likely to use the system".

Session Four

A Critique of the Concept of Normalization

Richard K. Myers

Although normalization appears to be a simple complex, it consists of at least three major principles:

1. *The principle of integration. While integration of the handicapped is a goal frequently discussed, it often is restricted to physical integration as opposed to more complex forms of integration, e.g. social, personal, etc. Moreover, considerable "backlash" appears to be occurring as a result of the high expense associated with the removal of barriers and other physical restraints to permit the handicapped population access to the physical environment.*
2. *The principle of self determination. The concept of normalization requires that the handicapped person receive the normal respect of others, the right to express their opinion relative to what happens to them and procedural due process. The stigma associated with most handicapping conditions remains as does the paternalism and other over protectiveness expressed by a majority of the public and many of the professionals who work with handicapped individuals. Our society has not resolved the conflicts associated with moving handicapped persons from invisibility to visibility, from dependency to independency, etc.*
3. *The principle of normal risk. While it is easy to state this principle, it is difficult to implement. Normal risk means the right to make decisions and fail as well as to succeed. Many individuals remain reluctant to permit handicapped individuals real control over their lives. This reluctance is the result of both traditional attitudes and practices and unresolved issues of liability.*

Normalization is both a process and a goal. It is a way of thinking as well as of behaving. The process by which a new concept is conceived and eventually adopted is complex but has been described.[1] *Conceptualization of the concept is well advanced. The concept has been widely accepted, especially among the professional and advocacy groups that work with the handicapped population. The concept has begun to be legitimized via the legislative and judicial process. We are beginning to see a body of law and judical decisions that reflect key principles derived from normalization. The next logical step, allocation of resources, also has begun but only sparingly and inconsistently. Resources continue to support programs and services that are inconsistent with the concept of normalization. For example, the reassignment of resources from residential facilities to community services has not as yet occurred*

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[1] *Flynn, R.J. and Nitsch, K.E. Normalization. Accomplishments to date and future priorities. In R.J. Flynn and K.E. Nitsch (Eds.), Normalization social integration, and community services. Baltimore: University Press, 1980.*

in very many locations. Much remains to be done before normalization becomes so imbeded into the thinking and behaving of people that it becomes institutionalized into the fabric of our society.

A number of problems remain to be resolved. The workshop participants attempted to identify and define a number of the major problems related to the acceptance and utilization of the concept of normalization within their organizations. Four of the problems indentified include:

1. *Deceptively simple. The apparent simplicity of the concept results in misinterpretation and misconception. "Everyone knows what the concept means", consequently, little effort may be exerted in attempting to understand the concept or to adhere to its principles in its implementation. The lack of understanding may result in the lack of consistency and/or abuse.*

2. *Limited empirical support. The lack of empirical support and the corresponding need to accept the concept of normliazation on "faith" remains a major problem to be resolved. There is no substantial data to prove that normalization results in handicapped persons who perform better or are happier, are better adjusted, etc. than they would have been without normalization. Normalization remains an ideology which may produce individuals who are zealots in their insistence that normalization principles are implemented "faithfully" according to their interpretation of the concept irrespective of the needs or wishes of the handicapped person(s) with whom they are involved.*

3. *Inconsistencies/incompatabilities. Normalization is not a consistent concept. Major principles conflict with one another. For example, the principle of integration may conflict with the principle of self determination. The right to be left alone may interfere with the right to treatment. While inconsistencies may be a reasonable expectation during the conceptualization of normalization, these inconsistencies will need to be resolved before widespread implementation can be expected to occur.*

4. *Potential for perversion. Due to the apparent simplicity of the concept, normalization is susceptable to being manipulated to the detrement of handicapped individuals. For example, normalization has been used to rationalize the existence of limited and/or the failure to provide the specialized services needed by handicapped persons. The term has been used by some providers to defuse their critics and by others as a term to hide behind.*

The participants attempted to summarize their understanding of the concept of normalization by identifying the pros and cons they believe are associated with the concept.

Selected Pros	*Selected Cons*
1. *Normalization is a humane philosophy*	1. *The potential for failure is greatly increased*
2. *The ideaology is politically and socially acceptable*	2. *Normalization increases the potential for handicapped persons to experience ridicule*
3. *Normalization provides enriching experiences for handicapped people*	3. *Moving the handicapped person from place to place in search of the LRE may create adjustment problems*

	Selected Pros		Selected Cons
4.	Normalization brings handicapped people back into the community	4.	The simplicity of the concept may permit manipulation and abuse
5.	It is a simple concept	5.	In the hands of poorly trained persons, normalization can be detremental
6.	The burden of dependency may be reduced or eliminated from parents and guardians	6.	Normalization may reduce handicapped persons' freedom of choice
7.	Normalization increases community acceptance of responsibility for handicapped citizens	7.	Normalization may interfere with attracting individuals to jobs working with handicapped individuals
8.	The handicapped person is likely to make more progress	8.	Normalization may increase social and emotional problems due to the increased adjustment problems encountered by handicapped individuals
9.	Normalization promotes economic self sufficiency	9.	Normalization may not be appropriate for all handicapped people
10.	The concept promotes independence and freedom	10.	The concept may be used as an excuse for not providing and/or curtailing needed community services
11.	Normalization should reduce the costs associated with providing specialized services for handicapped people	11.	The funds needed to implement normalization may be excessive in times of economy stagflation
12.	Normalization promotes full civil and personal rights for the handicapped person	12.	Normalization may result in loneliness and isolation for some handicapped individuals
13.	Normalization may contribute to a reduction in parental feelings of guilt		
14.	It promotes the development of local resources		
15.	More jobs may be created in the community for individuals to work with handicapped people		

Appendix

Participants

Jessie Asa
Deborah Crisan
Charles Grabe
Lori Landsettle
Lynda Means
Daniel Musko
Richard Myers
Alma Petrini
Phillip Rosenbauer
Donna Ross
Gail Russell
Mary Swayne
Karen Vanderzwaag
Waldo Vanderzwaag
Amy Walker

THE TECHNIQUES OF INFORMAL ADVOCACY

(from Introduction to Paralegalism - William P. Statsky)

"PUT YOUR CARDS ON THE TABLE:" be direct and completely above board in telling the agency official what your position is and what you want.

"DEMAND ADEQUATE SERVICE:" point out to the agency official that the purpose of the organization is service and that this principle should guide all actions.

"SEEK THE SUPPORT OF THIRD PARTIES:" before you make your position known, gather the support of individuals or groups within or without the agency so that you can demonstrate that you are not alone.

"BE FRIENDLY:" show the agency official that you are not his/her enemy and that you respect and like him/her and that you are aware of how difficult his job is.

"FIND THE POINTS OF COMPROMISE:" ferret out the negotiable points in the dispute and determine whether you can bargain your way to a favorable result.

"INSIST ON COMMON-SENSE:" convey to the agency official the impression that common-sense dictates the position you are advocating in addition to or in spite of the regulations or technicalities that might be cited against you.

"DEMONSTRATE THE EXCEPTION:" insist on uniqueness of your clients situation so that the general rule cited by the agency official to deny your client a benefit is shown to be inapplicable.

"UNCOVER THE REALM OF DISCRETION:" take the position that rules don't exist until they are applied and that in the application of rules, agency officials often have wide discretion in spite of their claim that their hands are tied by the rules.

"ASK FOR AUTHORIZATION:" insist that the agency official show you the regulation law or authority which supports the action he/she has taken or proposes to take.

"CITE THE LAW:" show the agency official that you know what administrative regulations apply to the case (and in some instance you also cite statutes and cases to demonstrate your point).

"REDEFINE THE PROBLEM:" if you can't solve a problem redefine it, if you can still provide what the client seeks, e.g., stop trying to qualify the client for program "Z" if program "Y" will serve him equally well and the problems of qualifying him for "Y" are not as great as those encountered in continuing to assist on "Z."

"ANGER/HOSTILITY:" be completely open about the bad feelings that you have about what is being done.

"PREACH:" perhaps the most common way in which people try to change other people is to lecture them, to tell them what they should or should not be doing.

"CLIMB THE CHAIN OF COMMAND:" normally everyone has a boss who can overrule decisions made by those beneath him/her. When you are dissatisfied with the decision or action of an employee, "appeal" or complain "up the chain of command" to the supervisor of the employee, and to the supervisor of the supervisor if needed.

"EMBARASS HIM:" show the agency official that you do not respect him/her in such a way that makes him/her look silly.

"MAKE CLEAR THAT YOU AND YOUR OFFICE ARE GOING TO FIGHT THIS CASE ALL THE WAY UP:" make the agency official aware of how important the case is; when you and your office have the grounds to back you, point out that you are thinking about taking the case to a formal agency hearing and that your office may go to court if necessary.

"DO A FAVOR TO GET A FAVOR:" be willing to do something (within reason) for the person from whom you are seeking something.

"SITE A PRECEDENT:" point out to the agency official (if it is true) that your case is not unusual because the agency has granted clients what you want under the same or under similar circumstances in the past.

LEGAL REFERENCES

PENNSYLVANIA CONSTITUTION

Article III, Section 14: "The General Assembly shall provide for the maintenance and support of a thorough and efficient system of public education to serve the needs of the Commonwealth."

PENNSYLVANIA LAWS AND REGULATIONS

School Code, Sections 1371-1377 (23 P.S. 13-1371 to 13-1377): These sections require identification and placement of, and free transportation for, all exceptional children in Pennsylvania.

The State Board of Education publishes regulations which school districts and intermediate units are required to follow. The regulations relating to special education, published at Title 22 of the Pennsylvania Administrative Code are:

Chapter 13 - The due process procedures for challenging an inappropriate educational classification or placement.

Chapter 171 - The procedures which must be followed in order to obtain state approval for the placement of a student in a private school for exceptional childre.

Chapter 341 - Definitions of different types of exceptionalities such as mental retardation, learning disability, gifted and talented, and the procedures which must be used in developing Individualized Education Programs (IEP's), and the rights of handicapped children subject to disciplinary proceedings.

FEDERAL LAWS AND REGULATIONS

Section 504, Vocational Rehabilitation Act of 1973 (29 U.S.C. 794): This law prohibits discrimination against and handicapped person by recipients of federal funds (including the State Department of Education and nearly all school districts). The regulations applying Section 504 to education programs appear at 45 C.R.F. 84.31 et seq. (Federal Register for May 4, 1977).

Education for All Handicapped Children Act (20 U.S.C 1401 et seq.): This law requires states receiving funds for education of the handicapped to provide a free appropriate program of special education and related services for all handicapped children. The regulations implementing the law are found at 45 C.F.R. Part 121a (Federal Register for August 23, 1977).

Resource References

Pennsylvania Directory of Advocacy Groups for Persons with Developmental Disabilities, D.D.A.N. 3540 North Progress Avenue, Harrisburg, Pa. 17110-9659 (717) 657-3320 - 1-800-692-7443

Legal Rights Handbook for the Developmentally Disabled. D.D.A.N. Same as above.

The Rights to Special Education in Pa. -A Guide for Parents. Education Law Center, Inc., 2100 Lewis Tower Bldg., 225 South 15th St., Philadelphia, Pa. 19102 - (215) 732-6655.

Making it Through the Maze. A Guide to Service in Pa. for Children with Emotional Problems. Education Law Center.

* D.D.A.N. Developemtal Disabilities Advocacy Network, Inc.

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INITIAL CASE INTAKE FORM :

ASSOCIATION FOR CHILDREN
WITH LEARNING DISABILITIES
230 E. JEFFERSON STREET
BUTLER, PA 16001

DATE : _____ PARENT'S NAME : _____

CHILD'S NAME: _____ ADDRESS : _____

DATE OF BIRTH : _____ PHONE : _____

AGE : _____ SCHOOL : _____

GRADE : _____ TEACHER: _____

REFERRED BY : _____

BRIEF STATEMENT OF PROBLEM :

PLACEMENT MADE IN :

FOLLOWUP OR RESULTS :

SERVICES (Check as needed)

serviced through public school system_____

serviced through parochial school system _____

serviced through private school system _____

evaluated through school system ____

evaluated outside of school system ____

placement in resource room -_____EMR____LD_____

individualized education program completed _____

related services

transportation
physical education
counseling; personal, vocational
guidance, parent training
speech therapy
physical therapy
social services

vocational education _____

due process _____

RECORDS AVAILABLE

What? (PSX,MED,ED,VOC.)
Where? 1. Agency _____
Address _____

2. Agency _____
Address _____

3. Agency _____
Address _____

ACTION TAKEN?ADVICE GIVEN:

Release by Client: Date _____